

CONFIDENTIAL

DRAFT

ETHICS ISSUES : ACTION BY HUGO

Discussion Paper

1. At the Moscow meeting of the Executive Committee, it was agreed that the handling of ethical issues should be discussed at the next Council meeting and the Secretary was asked to draft a paper as a basis for discussion.
2. There is general agreement that the Human Genome Project itself - the mapping and, eventually, sequencing of the human genome - does not raise any new ethical issues. However, the application of the knowledge acquired in the course of the project has given rise to public concern. The extent of the concern, and the particular causes of it, vary widely from country to country.
3. Both the US and the EC have set up Working Groups to review the ethical, social and legal impacts of their programmes (ELSI and ESLSA respectively). Various mechanisms have been used to address concern in other countries - review by national ethical committees, consensus conferences etc (though some have not seen any such need). In addition there have been a number of international meetings over the last 2 - 3 years, some sponsored by international organisations such as UNESCO, CIOMS, OECD.
4. A fairly general consensus about the principal causes of concern, though not about whether all are well-founded, emerged early on. It is frequently said that subsequent reviews continued to iterate the arguments without shedding new light. There also seems to be an increasing tendency to use the Human Genome project to attempt to set ethical standards for matters that are somewhat tangential.
5. At a recent conference in Bethesda (Human Genome Research in an Interdependent World : 2 - 4 June 1991) the participants concluded that an international co-ordinating/steering committee should be set up, with members drawn from the following, *inter alia* : HUGO, Japan, the Soviet Union, UNESCO, CIOMS, CAHBI, ESLI, ESLSA and the International Association of Bioethics. Subsequently, it was suggested informally that HUGO might provide the secretariat for this group. The Executive Committee discussed this in Moscow and concluded that :
 - it was not clear that anyone at the Bethesda meeting had an official mandate to propose the setting-up of such a group or that such an initiative would be welcomed by national authorities;
 - many of the concerns differ, sometimes, because of, deep cultural differences; setting up an international body required a clear, closely defined mandate separating national from common, international concerns;
 - HUGO should not act precipitately.

6. There are a number of topics which could usefully be addressed in-depth - not necessarily by HUGO. Among these are:
- diagnosis/screening. The WHO has run a number of successful screening programmes which are very acceptable to local populations. What can be learned from this?
 - confidentiality of genetic information. There are already attempts to legislate about this under consideration in Europe. Are these premature?
 - the use of genetic information in relation to employment. There is a good OTA report but the relevance of many of its conclusions outside the US is arguable.
 - life insurance. Nothing is known about the attitude of insurance companies.
 - medical insurance and the problems of countries without a National Health Service or equivalent.

7. POSSIBLE ACTION BY HUGO

7.1 HUGO's Ethics Committee.

Membership

This committee (Chair : V. McKusick : Core members : Muller-Hill, Niermeijer, Takebe) could be expanded so as to ensure cross-representation with some other bodies and yet others offered observer status. Membership of HUGO Committees is normally for 3 years (By-laws, Art 12) but in this Committee it could be shorter to allow for greater international representation while maintaining a manageable size.

Remit

The current charge to the Committee is :

- to produce a scholarly compilation of the issues.

In addition, Dr Charles Scriver has been asked to run a meeting, in North America, on the use of information about genetic variability in relation to insurance,

Support

The Committee needs a secretariat and may need additional funds to enable it to meet.

7.2 An international (steering) committee?

It is not clear what its remit would be. Information exchange already exists : for instance, ESLA has close relationships with CAHBI, UNESCO, ELSI. Duplication of effort cannot be avoided as many of the bodies have statutory remits which dictate it. A truly international viewpoint on many of the issues is next to impossible. The remit could be to collect information about legislation etc in different countries but this might well be viewed by the Third World as cultural imperialism. One positive aspect - but only if the prospective membership were different - would be to involve the Third World in discussion of the issues, without any attempt to dictate solutions.

It has been suggested that it is HUGO which should provide the global perspective. HUGO could offer its Ethics Committee (plus observers) as the "international committee" and invite support.

8. The Council is invited to consider :

- (i) whether to expand the membership of the Ethics Committee to take into account the need for cross-representation with other bodies and wider geographical/cultural representation;
- (ii) whether any tasks need to be undertaken by the Committee as a matter of urgency;
- (iii) what resources are needed and how to provide them;
- (iv) how to respond to the Bethesda initiative.